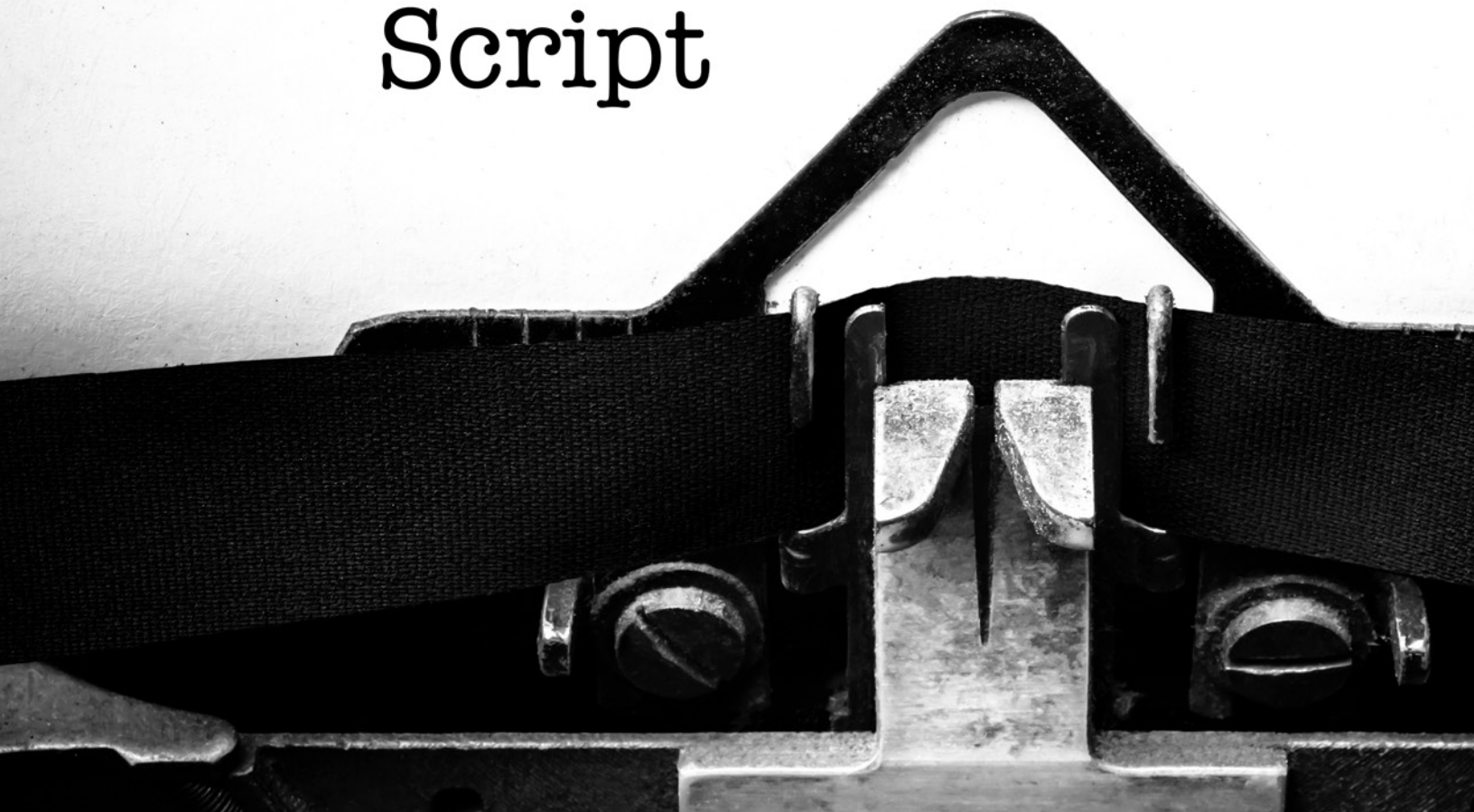


Rewriting the Script





**The future
belongs
to those
who believe
in the
beauty
of their
dreams.**

Eleanor Roosevelt

In 2015 as we wrapped up celebrating our 40th anniversary, the Tuberous Sclerosis Alliance (TS Alliance) began to set the stage for the next decade of TSC research and support. In 2016, with this foundation in place, we began rewriting the script on this disease and redefining what a patient-focused nonprofit can accomplish. 2016 demonstrated the only limit to what we can achieve is our own imagination.

So in the spirit of the founding mothers who refused to accept the status quo, the TS Alliance dared to imagine preventing the worst manifestations of TSC, creating a global network of support, and ensuring everyone with TSC has access to the resources they need to attain the highest quality of life.

Some 2016 highlights included:

- The Clinical Research Consortium started making history with the PREVeNT clinical trial—preventing epilepsy using vigabatrin in infants with tuberous sclerosis complex. PREVeNT is the first-ever preventative trial in the United States for any form of epilepsy and began enrolling participants in December 2016.
- Three pharmaceutical companies joined the organization's Preclinical Consortium in 2016. The consortium initiated epilepsy experiments in August 2016.
- The TS Alliance announced the creation of the Engles Collaborative Research Fund, following a pledge of \$1.5 million by Gregg and Molly Engles through the Engles Family Foundation. The pledge also prompted the creation of the TS Alliance President's Council.
- In celebration of TSC Global Awareness Day on May 15, Tuberous Sclerosis Canada Sclérose Tubéreuse (TS Canada ST) and the TS Alliance announced a joint partnership to enhance community support, clinical care and research efforts in North America.
- On December 14, 2016, the TS Alliance launched its redesigned website, tsalliance.org. The new site features an easy-to-navigate interface with content developed for specific audiences, including newly diagnosed families and individuals, healthcare professionals, researchers and donors. The website was also created with responsive design to allow for easy viewing on phones, tablets and other mobile devices.
- In partnership with The LAM Foundation, the TS Alliance hosted three Regional TSC Conferences held in Nashville, TN; Seattle, WA; and Cleveland, OH with 180 combined attendees.

This annual report provides an overview of the organization's efforts and achievements in 2016, and while much work remains in our quest to better the lives of everyone affected by tuberous sclerosis complex, the TS Alliance knows we are building a brighter future together with our community, partner organizations and other supporters.

About the Tuberous Sclerosis Alliance

The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected by:

- Developing programs, support services and resource information;
- Stimulating and sponsoring research; and
- Creating and implementing public and professional educational programs designed to heighten awareness of the disease.

With these goals in mind, the TS Alliance is the only organization able to rally the financial resources, the research, the partnerships and the sheer will of TSC-affected families and individuals to work toward a future in which no one has to endure the devastating effects of TSC.



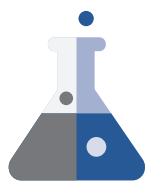
What is Tuberous Sclerosis Complex?

Tuberous sclerosis complex—or TSC—is a genetic disorder that causes tumors to form in vital organs, primarily the brain, eyes, heart, kidney, liver, skin and lungs. TSC is a highly variable disease. Some people with TSC live independent, healthy lives and enjoy challenging professions such as doctors, lawyers, educators and researchers. Others with the disease often experience uncontrollable seizures, autism, heart disease, learning and behavioral problems, facial disfigurement, kidney failure and, sometimes, even death.

In addition, TSC is the leading genetic cause of both autism spectrum disorder and epilepsy. Up to 50 percent of people with TSC develop autism, while about 85 percent experience seizures at some point during their lives. Approximately 80 percent of those with TSC develop kidney lesions.

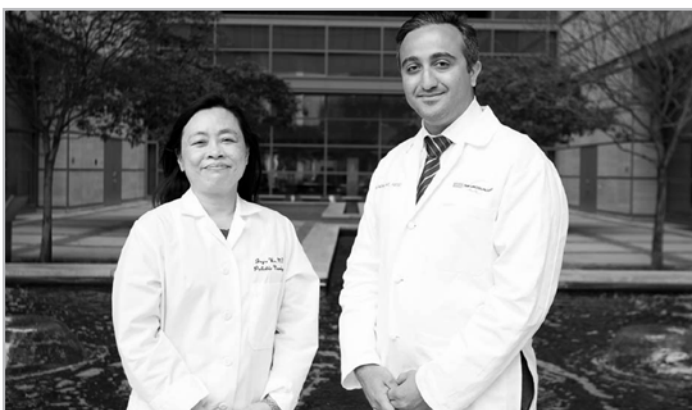
While there is currently no cure, this annual report shows why so much hope is on the horizon for anyone touched by TSC.

Expanding TSC Research



The TS Alliance's Research Program stimulates and supports basic, translational, and clinical research on the various manifestations of tuberous sclerosis complex (TSC) to further the development of clinical therapies and, ultimately, a cure for TSC. The TS Alliance

has funded more than \$19.7 million in research on TSC since 1984. Directed by Steven L. Roberds, PhD, Chief Scientific Officer, the TS Alliance Research Grants Program funds research focused on TSC proposed by researchers and aligned with the research priorities of the TS Alliance. Collaborations between basic and clinical researchers are encouraged and fostered, for example, by biennial International TSC Research Conferences.



Dr. Joyce Wu and Dr. Aria Fallah of UCLA

In 2016 the TS Alliance Research Grants Program funded a total of 15 research awards for \$887,095. The TS Alliance continued to support eight research grants awarded in previous years. Additionally, seven new research awards were funded beginning in 2016 to:

- Dr. Heng-Jia Liu (Brigham and Women's Hospital) for a postdoctoral fellowship to study T-cell dysfunction in TSC;
- Dr. Peter Davis (Boston Children's Hospital) to study brain network biomarkers of epilepsy in TSC;
- Dr. Jonathan Lipton (Boston Children's Hospital) to study the circadian clock as a capacitor for TSC-related phenotypes;
- Dr. Mark Nellist (Erasmus Universitair Medisch Centrum Rotterdam) to functionally characterize TSC1 and TSC2 variants associated with TSC;
- Dr. Carmen Priolo (Brigham and Women's Hospital) to study the lysophosphatidic acid pathway in TSC;
- Dr. Peter Tsai (University of Texas Southwestern Medical Center) to study the impact of cerebellar-medial prefrontal cortical circuits in TSC; and
- Dr. Darcy Krueger (Cincinnati Children's Hospital Medical Center) to develop a clinical protocol to test the ability of mTOR inhibitors to prevent manifestations of TSC.



Implemented in 2006, the TSC Natural History Database captures clinical data to document the impact of the disease on a person's health over his or her lifetime. As of December 2016, 2,070 people with tuberous sclerosis complex were enrolled in the project from among 18 U.S.-based sites. The TS Alliance provides funding to participating clinics to perform data entry, monitors the integrity of the database, and makes data available to investigators to answer specific research questions and identify potential participants for clinical trials and studies. In 2016, the TS Alliance invested \$431,054 in the TSC Natural History Database and implemented sub-projects on renal angiomyolipomas and subependymal giant cell astrocytomas (SEGA) to address detailed questions about these life-threatening manifestations of TSC. A contract with Novartis executed in November 2012 was extended to provide the TS Alliance with funding to enhance and grow the depth of data in the TSC Natural History Database through 2018.



The TSC Biosample Repository is a TS Alliance-directed project initiated in 2014 that will impact research over the next ten years or more. High-quality biosamples such as blood, DNA, and tissues linked to detailed clinical data

are required for researchers to understand why TSC is so different from person to person. Such samples are currently unavailable, and the TS Alliance's Science and Medical Committee identified this as a gap that can only be filled effectively with leadership of the TS Alliance, guided by a steering committee of clinicians and researchers. Samples in the repository are linked to detailed clinical data in our existing TSC Natural History Database and are available to qualified researchers worldwide. Samples are housed at and distributed from the Van Andel Institute in Grand Rapids, MI, under control of the TS Alliance. The TSC Biosample Repository has collected 176 blood samples from voluntary participants enrolled in the TSC Natural History Database at Texas Scottish Rite Hospital, Nicklaus Children's Hospital in Miami, and Minnesota Epilepsy Group, and from Rare Diseases Clinical Research Network (RDCRN) participants at Boston Children's Hospital, Cincinnati Children's Hospital, the University of Alabama at Birmingham, University of Texas Health Science Center at Houston, and the University of California, Los Angeles (UCLA). The Biosample Repository is generously supported by The Cowlin Foundation, Engles Family Foundation on behalf of Engles Collaborative Research Fund, Jim and Andrea Maginn, and William Watts.



Dr. Andrew Tee's video update on progress made from the #IAMTSC | We Are TSC 50K Crowdfunded Research Challenge



The **TSC Preclinical Consortium** enables prioritization of candidate treatments based on comparing head-to-head data using consistent animal models and rigorous testing procedures. The TS Alliance is ideally positioned to drive this collaboration—with input

from academic, regulatory, and industry stakeholders—by maintaining constant focus on the needs of people with TSC. The TS Alliance obtained licenses to use specific TSC mouse models for experiments carried out by the Preclinical Consortium, and all mouse license agreements include the rights for the TS Alliance to perform experiments under contract for commercial entities. This ensures data generated by the Preclinical Consortium can be used to accelerate the development of new treatments by commercial entities as well as academic investigators. Three pharmaceutical companies joined the Preclinical Consortium in 2016. Additionally, four other companies have expressed serious interest. The consortium began running epilepsy experiments in August 2016 at a contract research organization, PsychoGenics, Inc. The TSC Preclinical Consortium is supported by The Cowlin Foundation and Engles Family Foundation on behalf of Engles Collaborative Research Fund.



The TS Alliance continued to be a key part of the **TSC Clinical Research Consortium** although only a small amount of TS Alliance financial support was required because of the consortium's success in obtaining National Institutes of Health (NIH) funding. Now consisting of seven sites—Boston Children's Hospital, Cincinnati Children's Hospital, the University of Alabama at Birmingham, the University of Texas Health Science Center at Houston, UCLA, Stanford University, and Minnesota Epilepsy Group—the consortium has received \$29 million in competitive grant funding from the National Institutes of Health (NIH) to support clinical studies in TSC. The Clinical Research Consortium is making history with the **PREVeNT** trial—Preventing epilepsy using vigabatrin in infants with tuberous sclerosis complex. PREVeNT is the first preventative trial for any form of epilepsy in the United States and began enrolling participants in December 2016. The PREVeNT trial builds directly upon the Consortium's first clinical study from which interim results have been published showing all infants who developed abnormal activity on EEGs went on to experience seizures. This trial will determine whether treatment with vigabatrin prior to the onset of clinical seizures in TSC is beneficial to children's developmental and neurologic outcomes. The TS Alliance's Chief Scientific Officer serves on the consortium's leadership team.



The PREVeNT trial tests the intriguing hypothesis that by intervening before clinical symptoms appear we might change the course of TSC's neurologic manifestations. This would be truly exciting.

Walter Koroshetz, MD, Director of the National Institute of Neurological Disorders and Stroke

Dr. Elizabeth Henske receives the American Thoracic Society (ATS) Public Advisory Roundtable (PAR) Excellence Award from TS Alliance, The LAM Foundation and ATS PAR representatives



Providing Outreach and Support

Our Outreach Department develops programs and services that provide individuals with TSC direct access to information, resources, and specialists experienced in the diagnosis, treatment and management of TSC.

The Outreach Department provided direct support and resources to 3,307 individuals and families dealing with TSC throughout 2016. The Vice President of Outreach attended 65 school meetings (IEPs, Evaluation Team Meetings, 504 Plan Meetings, Resolution Meetings, and Mediations) in person, through SKYPE or Facetime, and via conference calls to support families in attaining educational services for their children throughout the country. In 2016, 24 Educational Liaison volunteers worked in 24 states to connect families to free educational advocacy trainings in collaboration with the states' Parent Training and Information Centers. As a result, more than 2,344 free parent trainings/webinars on educational advocacy were offered to families dealing with educational issues for their children. In addition, the Educator Mentor Program supported 89 school systems in understanding the learning needs of children with TSC.

Through a network of 37 volunteer branches of the organization, called Community Alliances, local education and support group meetings were held throughout the country. Through these Community Alliances, the TS Alliance hosted 76 educational meetings and gatherings. Among these 76 meetings was a 13-meeting Town Hall educational series. The series highlighted transition services offered by The Arc. These Town Hall meetings were hosted in TSC clinics and other venues across the United States with 160 people attending. One new Community Alliance, the TS Alliance of Kentucky/West Virginia, was added in 2016.

The TS Alliance facilitated 13,540 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors and Dependent Adult Transition Resource Coordinators and through Community Alliance meetings.

In partnership with The LAM Foundation, the TS Alliance hosted three Regional TSC Conferences held in Nashville, TN; Seattle, WA; and Cleveland, OH with 180 combined attendees. These conferences brought together individuals, parents, caregivers and members of the medical community to provide the most up-to-date information so parents and adults with TSC can make informed decisions when evaluating treatment options. The one-day symposiums offered educational outreach, information on the latest treatments in TSC, research updates, and support options. They featured the region's top experts and provided attendees the opportunity to have one-on-one meetings with these experts in a nurturing, supportive environment. Regional TSC Conferences provide much-needed forums for the growing number of people facing the daily challenges of TSC.



Adult Regional Coordinators Rob and Shannon Grandia, Jake Irby, Brooke Simsa and Seth Fritts with Vice President of Outreach Dena Hook at the March on Capitol Hill

The TS Alliance facilitated 13,540 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors and Dependent Adult Transition Resource Coordinators and through Community Alliance meetings.

Increasing Awareness

The TS Alliance diligently works to heightens awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2016, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to 15,000-plus constituents as well as posted on the website.



The TS Alliance's website increases awareness and provides extensive education through an average of more than 40,000 unique visitors each month; the site was completely redesigned in 2016 and launched December 14. The TS Alliance also relies heavily on social media to educate constituents and promote new resources and events. Its Facebook Group boasts more than 7,800 members, while its Twitter account has 1,600-plus followers and Inspire boasts 4,411 participants from 103 countries.

TSC Global Awareness Day

May 15

To increase public awareness, the TS Alliance once again participated in TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May; a TSC Global Awareness Day news release garnered 13.6 million impressions.

The TS Alliance again heavily promoted Infantile Spasms Awareness Week with 16 partner organizations, December 1 to 7. This awareness campaign included social media, advertising to first line physicians and parents, and a media tour. Facebook advertising to reach misdiagnosed or those seeking a diagnosis reached 272,936 people. Advertising to first line physicians included an American College of Emergency Physicians newsletter ad with 37,249 subscribers and an American Academy of Pediatrics News ad reaching 64,805 readers. The satellite media tour featured Dr. Martina Bebin and Hope Award Winner Ellen Wehrman with 33 aired interviews (21 TV/12 radio) reaching a total audience of 6.1 million (309,712 broadcast and 5,801,947 radio).



2016 Infantile Spasms Hope Award recipient Ellen Wehrman with TS Alliance President & CEO Kari Luther Rosbeck and Child Neurology Foundation Executive Director Amy Brin Miller, MSN, MA, PCNS-BC



Drs. Kevin Ess and Lisa Young pose with TS Alliance and The LAM Foundation staff at the TSC Regional Conference in Nashville, TN

Educating Healthcare Professionals

Professional Education expands programs to target researchers and healthcare providers caring for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation.

The TS Alliance participated in and presented at 27 professional meetings including: The Child Neurology Society Meeting; LAMposium and the LAM and Rare Lung Disease Conference; World Orphan Drug Congress; Association of Clinical Research Professionals Conference; Interagency Collaborative To Advance Research In Epilepsy (ICARE); FDA Patient Engagement Workshop; Partners Against Mortality in Epilepsy (PAME) Conference; 2016 Vancouver TSC Educational Conference in British Columbia; The NINDS Nonprofit Forum; Disability Policy Seminar; the Indication Expansion and Drug Repurposing Summit; CBI's Patient Registries Summit; 3rd Rare Disease Collaborative Summit hosted by EXL Events; Society for Neuroscience Annual Meeting; BIO Patient and Health Advocacy Summit; NORD Summit; the International TSC Research Conference in Portugal; and the American Thoracic Society meeting. In addition, at the American Epilepsy Society (AES) annual meeting the TS Alliance hosted an Infantile Spasms Awareness Innovation Pavilion exhibit and a TSC reception for more than 100 researchers, clinicians, and community members. The TS Alliance also participated in two Special Interest Group scientific sessions, one on TSC and another on research resources made available by nonprofit organizations advocating for rare disorders that involve epilepsy.

Further, the Vice President of Outreach has ongoing partnerships with national educational networks, such as the Association for Middle Level Education (AMLE) and The Arc of the United States. She also collaborates with Parent Training Information Centers (PTIs) throughout the country. Providing children with appropriate education is one key to individuals having a good quality of life.

Advocating at the Federal and State Level

The organization's government advocacy efforts focus on educating members of Congress about TSC to further TSC research, awareness and clinical care. The annual **TS Alliance March on Capitol Hill** to advocate for federal funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP) took place in early March 2016. More than 100 members of the TSC community participated and asked their senators and representatives to sign onto Dear Colleague letters in support of the TSCRP. Many other advocates who were not able to travel to Washington, DC met with their senators and representatives back in their home states to make the case for continued funding. In the House, 165 Democratic and Republican Representatives signed a bipartisan Dear Colleague letter of support from Representatives Loretta Sanchez (D-CA) and Mike Fitzpatrick (R-PA). The Senate letter was sponsored by Senators Chris Murphy (D-CT) and Johnny Isakson (R-GA) and ended with 25 signatures.



Community volunteers at the 2016 Volunteer Appreciation Dinner

In FY2016, the TSC Research Program (TSCRP) at the CDMRP received a \$6 million appropriation, bringing the cumulative funding to \$65 million since 2002 as a result of our successful grassroots efforts. Funding for FY2017 was still pending on Congress passing the FY2017 budget as of December 31, but was included in the House's 2017 Defense Appropriations Act at \$8 million. The \$2 million increase over past years is due to an amendment put forth by Rep. Fitzpatrick during the House floor debate on the Defense Appropriations Act on June 15, 2016.

Research performed through this program has recently led to additional clinical trials including determining if imatinib, a drug FDA-approved for cancer, can safely improve levels of VEGF-D, a biomarker of lymphangioleiomyomatosis (LAM), a life-threatening lung manifestation of TSC, funded in FY2013 (the most recent year for which awards have been announced); testing a combination of two drugs to treat LAM funded in FY2012; a multi-site clinical trial testing the efficacy of an experimental topical rapamycin cream to treat the disfiguring facial tumors, called facial angiofibromas, caused by TSC funded in FY2010; a clinical research network was created to test potential new therapies, to

validate biomarkers, and to learn the natural history of leading to a clinical trial funded in FY2012. Building upon FY2010-funded research on glutamate receptors (mGluR5), several companies are now looking at the link between cognitive impairments in TSC to autism, anxiety, and other mental disorders. The TSCRP has also funded research to develop animal models of TSC that have seizures, enabling a better understanding of the etiology of TSC. Based on data from TSCRP-funded animal models of TSC that have seizures and share pathology related to that of traumatic brain injury, an industry-sponsored clinical trial demonstrated the effectiveness the mTOR inhibitor, everolimus, at treating epilepsy in many individuals with TSC. None of this progress would have been possible without the critical support provided through the TSCRP.

Additional Government Relations efforts included a **Congressional Briefing** on Capitol Hill on March 2, 2016. Congressional staff and key members of the TSC research and grassroots communities attended the event, with Shelly Meitzler giving a moving personal testament to the value of TSC research through the CDMRP.

Establishing Global Alliances

Officially launched in 2014 with the TS Alliance of Israel, the **Global Alliance** program fosters stronger links between the TS Alliance, communities and individuals around the world. A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TS Alliance to facilitate local connections for individuals and families affected by TSC, raise revenue and increase awareness while supporting the mission of their organization.

On May 15, 2016, in celebration of TSC Global Awareness Day, Tuberous Sclerosis Canada Sclérose Tubéreuse (TS Canada ST) and the TS Alliance announced they joined in a partnership that will enhance community support, clinical care and



TS Alliance of Israel board members with TS Alliance staff and President of the TS Alliance of Mexico at the Western Wall in Jerusalem

research efforts in North America. The TS Alliance will provide a variety of services to TS Canada ST to build on their exceptional reputation of constituent support, ranging from educational conferences to global clinical trials education and recruitment to designation of TSC Clinics to helping identify and serve a wider constituency. TS Canada ST will also have one ex-officio position on the TS Alliance Board of Directors.

In December, the TS Alliance signed Global Alliance agreements with **TS Alliance Mexico** and **TS Alliance Foundation** based in Thailand.

Raising Funds to Support Our Mission

The TS Alliance's ability to achieve our lofty ambitions is made possible through the tenacity and heartfelt dedication of the TSC community. Whether by supporting TS Alliance national events, raising awareness at walks across the country or holding community fundraisers, our loyal supporters continue to champion our shared cause and their donations, large and small, drive our ability to provide resources and support to everyone affected by TSC. Furthermore, the incredible generosity of TSC community members continues to inspire the TS Alliance to create new initiatives to accelerate current research efforts and truly drive the next generation of breakthroughs.

The TS Alliance President's Council was introduced following a pledge of \$1.5 million by Gregg and Molly Engles through the Engles Family Foundation on behalf of Engles Family Collaborative Research Fund. The President's Council, comprised of members of families impacted by TSC, works with the President & CEO and Board of Directors to drive research forward through significant contributions given and/or solicited to the **Unlock the Cure – Accelerate, Collaborate, Target (ACT) Now!** campaign. The President's Council differs from the TS Alliance Board of Directors in that members have no fiduciary responsibility for the organization and advice is non-binding. However, their counsel and assistance in raising substantial capital for the organization will have a profound impact on exceeding **Unlock the Cure** aims.



Gregg and Molly Engles and family

The President's Council exists to dramatically advance scientific progress by ensuring resources exist to make strategic results possible, thereby improving the quality of life for those living with the disease today and in future generations. Members of the President's Council are tasked with the following:

- Give or get a minimum gift of \$100,000 per year for two years to fuel **Unlock the Cure – ACT Now!**
- Identify potential individual, corporate or foundation donors.
- As needed/necessary make introductions or schedule appointments with contacts to discuss research opportunities.
- Review **Unlock the Cure – ACT Now!** fundraising materials.
- Work with TS Alliance staff in generating tailored requests based on donor interests or requirements.
- Help to identify other potential sources or strategies effective in obtaining federal or state research funds and making personal calls and introductions.

Current TS Alliance President's Council Members include: Gregg and Molly Engles, Engles Family Foundation on behalf of Engles Collaborative Research Fund, and William Watts.

Unlock the Cure – ACT Now! in its second year of phase two raised \$3,628,673. The Unlock the Cure campaign helped the TS Alliance develop a Drug Screening Program, identify biomarkers, develop a Clinical Research Consortium, expand the TSC Natural History Database, and increased support for the TS Alliance Research Grants Program. The next phase will continue to expand on these efforts and add additional focus to developing a Biosample Repository, Preclinical Consortium and preventative treatments for TSC.

Special Events

In 2016, special events netted \$1,361,359 representing 26% of the organization's overall revenue. A few highlights include:

Comedy for a Cure® Hollywood celebrated its 15th anniversary in 2016 at the Globe Theatre at Universal Studios Hollywood, and raised \$199,449. The evening featured fabulous music from Chris Hawkey, Kat Perkins and Eric Warner followed by hilarious performances by Wendy Liebman and Bobby Collins. We were also joined by our gracious Honorary Chair Jim O'Heir and Emcee Alex Skuby. The TSC community is so fortunate to have such a fantastic group of celebrity supporters who continue to champion our cause. We were humbled to present the Courage in Leadership Award to Barbara O'Neill and her daughter, Dawn O'Neill Redfield, and their families for their incredible contributions. Honoree Tributes were given to Mo Collins and Ken Kocher for their years of commitment to TSC. The event was dedicated Dee Triemer, a TSC mom, advocate and staff member who lost her battle with cancer in 2015. We thank all our partners for making the evening possible and helping raise \$196,000 including the fabulous Comedy for a Cure planning committee, auctioneer Sean Endicott, Ingram Design Studio, Traci Hoffberg Events and Tom Bercu Presents, as well as our incredible major sponsors including Lundbeck, Mallinckrodt, MarketCast, Novartis, Variety, C&C Market Research, CVS Health, Emily's Family & Fan Club - the Szilagyi Family, Hallett Family Foundation, The Family of Brandon Kocher, The Maginn Family, WNC & Associates Inc., Warren and Diane Burgess, David and Cathy Krinsky, Richard and Lauren Packard, Edina Kiss, LIDS, MyCupCounts.org and Tom Bercu Presents.



Performers and celebrity supporters Shane Brady, Kat Perkins, Alex Skuby, Mo Collins, Jim O'Heir, Wendy Liebman and Chris Hawkey at the 15th annual Comedy for a Cure

The LIDS Step Forward to Cure TSC® walks took place in 34 cities across the United States and collectively raised \$1,052,858, and the TS Alliance was thrilled to have LIDS as our title sponsor. The walks are both fundraisers and community gatherings and it is inspiring to see the TSC community support these events and share their experiences on social media and with incredible news coverage in some areas. Julianne Moore once again served as our National Honorary Chair with support provided by national sponsors Lundbeck, Novartis, LIDS, GW Pharmaceuticals, Pillar Hotels and Resorts, MetLife Center for Special Needs Planning and MyCupCounts.org.



The LIDS Step Forward to Cure TSC® National Walk on the Mall took place at the National Sylvan Theater raising more than \$87,000 while also increasing awareness of TSC in our nation's capital. This walk was a great success thanks to the TSC community and the generous support from LIDS, Lundbeck, Novartis, GW Pharmaceuticals, Pillar Hotels and Resorts, MetLife Center for Special Needs Planning, MyCupCounts.org, Cavarocchi Ruscio Dennis & Associates, SAIC, Buffalo Wild Wings and Caribou Coffee.

Sound Bites was held in Golden Valley, Minnesota and featured an evening of food, wine and music. Guests enjoyed an intimate acoustic concert with Chris Hawkey, Kat Perkins, Eric Warner and Gunnar Nyblad, and we were thrilled to have Jim O'Heir of *Parks & Recreation* to emcee this incredible event. We are grateful to the wonderful restaurants who donated small tastes of their cuisine, including 508 Bar and Restaurant, Buffalo Wild Wings, Cooper, D'Amico and Sons, The Loop Restaurant, McCoy's, Mediterranean Cruise Café, Potbelly Coon Rapids, and The Red Cow. The Courage in Leadership Award was presented to the Ihle Family and an Honoree Tribute was given to Sarah Hoey for her steadfast commitment to the TSC community. We thank all our partners for making the evening possible and helping raise \$48,417 including the Sound Bites planning committee, Ingram Design Studio, as well as our incredible major sponsors including Minnesota Epilepsy Group, Michael and Janie Frost, Novartis, GW Pharmaceuticals, Lundbeck, Attract, Upsher-Smith, Fulton Beer and Caribou Coffee.

Events Raising More Than \$10,000

Signature National Events

- Comedy for a Cure®
- Sound Bites

Step Forward to Cure TSC Walks

- Alabama – Margaret Cox
- Arizona – Deborah Moritz
- Atlanta/North Georgia – Sharon Carpenter
- Carolina Hilton Head – Amy Bredesen
- Chicago (Westmont) – Geri Greenberg
- Connecticut – Rebecca Thereault
- Dallas – Planning Committee
- Delaware/Lehigh Valley – Shelly Meitzler and Bridget Simmons
- Delta Region – Katie Christensen
- Houston – Planning Committee
- Indiana – Pat Schmutte
- Michigan – Treasa Bolger-Dunlap
- Metro DC National Walk on the Mall – Brooke Carpenter
- Nashville – Planning Committee
- New England – Stacie Verrill
- New York (Long Island) – Carol Ann White and Lori DeStefano
- New Jersey – Tresha Bisang
- Northern California – Brittany Walsh
- Rocky Mt. Region – Alison Brainard
- Seattle/Pacific NW – Devon McCollum and Gloria Triebenbach
- Southern California – Barbara O'Neill and Dawn Redfield
- St. Louis – Gwen Montaigne
- Upper Midwest – Judy Prudhomme and Maria Gibbons
- Western Pennsylvania – Kelsey Hudson

Community Events

- 9th Annual TSC Fundraiser – Rob and Denise Spear
- 11th Annual Friends and Family BBQ for TSC – Bill and Nancy Youmans
- Crashin' for the Cause – Joe and Abby Kopf
- Krewe for a Cure – Margaret Cox
- Rock for Riley – Melanie Vogel
- Strikeout TSC Softball Tournament – Laura Laramie



Annual Fund - Major Donors and Contract Revenue

Fiscal Year 2016: January 1 to December 31

Chairman's Circle (\$100,000 and Above)

The Cowlin Foundation
Engles Family Foundation on behalf of
Engles Collaborative Research Fund
Lundbeck Pharmaceuticals, Inc.
Novartis Pharmaceuticals Corporation
OPL Charities
Tuberous Sclerosis Alliance Endowment Fund
William Watts

Benefactor (\$50,000 - \$99,999)

Harold Simmons Foundation
James and Andrea Maginn
Mallinckrodt Pharmaceuticals

Sponsor (\$20,000 - \$49,999)

Crashin' for the Cause, Eldorado Lions Club
GW Pharmaceuticals, Inc.
LIDS Foundation
The MetLife Center for Special Needs Planning
The Pediatric Epilepsy Research Foundation
John Pietrolungo
UCB, Inc.
The Winifred M. Gordon Foundation

Protector (\$10,000 - \$19,999)

Aimbridge Hospitality, LLC
Craig and Cindy Cunningham, C&C
Market Research
Richard and Lori Day
Michael and Janie Frost
Genesco
Christy Hobart and Henry Shapiro
David and Cathy Krinsky
Laura Laramie
The Louis Berkowitz Family Foundation, Inc.
MarketCast
Julianne Moore and Bart Freundlich
Ned Neely
Allan and Carla Price
Nancy Richards
Irene Rothberg
Rob and Denise Spear, The 8th Annual
Tuberous Sclerosis Alliance Fundraiser
Kevin and Melanie Vogel
Karen White and Julie Geissman
Whittingham Foundation

Defender (\$5,000 - \$9,999)

Steve and Lynn Aguiar
America's Charities
ARMATURE Corporation
The Bayless Family Foundation
Warren and Diane Burgess
Scott Clarkson, Glacier Design Systems, Inc.
Will and Kay Cooper, WNC & Associates, Inc.
CVS Health
Donelle Dadigan
Cornelius and Linda DenHarder
Tim and Kathi Dills
DoTopia
Tony and Linda Ellrod
Tony and Rhonda Gatti
The Gertrude and Philip Hoffman
Philanthropic Fund of the Jewish Federation
of Greater Pittsburgh
Dawn Grove
Keith and Andrea Hall
Hallett Family Foundation
Carol Hoffman
Indiana Oxygen
James Allyn, Inc.
Michael and Ann Johnson
William and Debra Joseph
Kenvo Foundation
Ken and Beth Kocher
Herbert and Carol Marton
Theodore and Peggy Mastroianni
Maurice Amado Foundation
Medtech
Scott and Kasandra Merrill
David and Nancy Michaels
Minnesota Epilepsy Group, P.A.
Robert and Staciellen Mischel, The Mischel
Family Foundation
Tim Missey
Jon and Patricia Myers
Jim O'Heir
Clark and Temple Poche
Ramesh and Kalpana Bhatia Family
Foundation
Chris and Leslie Russell
SAIC
Shawn Gaffney Memorial Fund
James and Judy Shoulak
Annie Szilagyi
Upsher-Smith Laboratories, Inc.
Variety - The Children's Charity
Lorne and Heidi Waxlax
Cliff and Debora White, Cliff and
Debora White Family Foundation
Kevin and Sarah Wright

Advocate (\$1,000 - \$4,999)

A. Sturm & Sons Foundation, Inc.
A.H. Management Group, Inc.
Leonard Abruzzo
Accurate Healthcare, Inc.
Acorda Therapeutics
Howell and Madeline Adams
James and Lee Ann Addison
Janice Akridge
Farid and Faranza Ali
Amazon Smile Foundation
Johnny Anderson
Rebecca Anhang Price and Matthew Price
Gregory and Nancy Annick
Anonymous
Marisa Antonini
Apex Right of Way Services, LLC
Arborscapes, LLC
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The TS Alliance strives to correctly recognize all our donors. We apologize in advance for any errors, omissions or misspellings in this annual report. Please contact our Development Department at (800) 225-6872 with any corrections.

Endowment Fund

The TS Alliance Endowment Fund is a separate fiduciary organization specifically chartered to receive gifts that will be invested to generate an income stream to help fulfill the mission of the TS Alliance. The Endowment Fund ensures the TS Alliance has an ongoing source of funding to better serve those touched by TSC through education, support services and research.

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When individuals and families inform the TS Alliance of a designated planned gift through a will or estate plan to the TS Alliance Endowment Fund or the TS Alliance they become part of the Eternal Flame Society. If you or a loved one has designated the TS Alliance through a planned gift and are currently not listed in The Eternal Flame Society, please let us know so we can add you. We are pleased to honor the following distinguished members of the Eternal Flame Society:

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On gifts of \$25,000 or more (with a pledge payable over five years), a donor has the opportunity to name a fund in honor of someone. We are deeply grateful for the following named funds:

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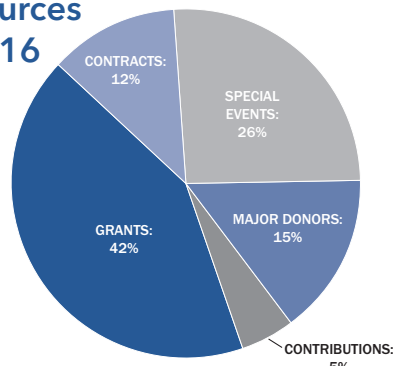
National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position • December 31, 2016 and 2015

As of December 31,	2016	2015
Assets		
Current Assets		
Cash and cash equivalents	\$ 1,975,799	\$ 2,767,106
Short-term investments	779,808	762,809
Accounts receivable	262,025	2,548
Promises to give - current portion	683,294	242,500
Prepaid expenses and other assets	182,942	110,268
Total current assets	3,883,868	3,885,231
Long-term investments	5,214,829	4,689,245
Property and equipment	190,332	146,437
Promises to give - non-current portion	797,694	73,697
Total assets	\$ 10,086,723	\$ 8,794,610
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 320,774	\$ 37,692
Accrued compensation	203,109	148,301
Deferred rent and lease incentive - current portion	22,318	19,525
Gift annuity obligations - current portion	12,530	12,530
Deferred revenue - current portion	39,476	-
Total current liabilities	598,207	218,048
Deferred rent and lease incentive - non-current portion	60,584	82,903
Gift annuity obligations - non-current portion	69,228	73,048
Deferred revenue - non-current portion	92,500	-
Total liabilities	820,519	373,999
Net assets		
Unrestricted		
Undesignated	520,953	1,002,282
Designated	4,782,158	4,641,486
Total unrestricted	5,303,111	5,643,768
Temporarily restricted	3,083,649	1,897,399
Permanently restricted	879,444	879,444
Total net assets	9,266,204	8,420,611
Total liabilities and net assets	\$ 10,086,723	\$ 8,794,610

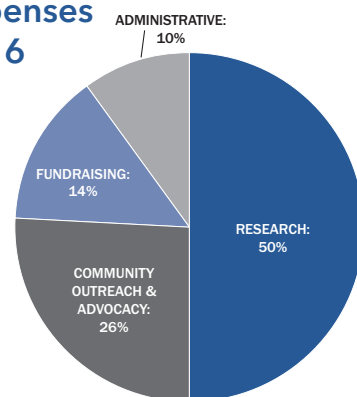
The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2016 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the TS Alliance or available on its website. To obtain a copy, please call (800) 225-6872 or download at www.tsalliance.org. This summary was prepared from the audited consolidated statements of the TS Alliance and the TS Alliance Endowment Fund. The relationship of the organizations requires consolidation per generally accepted accounting principles in the United States. Supporting services reflected in the consolidated statements of activities include services for both the TS Alliance and the TS Alliance Endowment Fund. The Endowment Fund may experience gains or losses on its investments. In 2016 there was a net gain and in 2015, a net loss on investments, contributing to the total change in net assets on a consolidated basis for each of those years. On a stand alone basis, operations of the TS Alliance generated a positive change in net assets of \$315,122 in 2016 and \$97,846 in 2015.

Operating Revenue Sources 2016



NOTE: These are the stand-alone revenues of the TS Alliance.

Operating Expenses 2016



NOTE: These are the stand-alone expenses of the TS Alliance

National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2016 Total	2015 Total
Revenue and Support					
Special Events	\$ 1,358,381	\$ 93,378	\$ -	\$ 1,451,759	\$1,582,972
Cost of direct benefits to donors	(120,399)			(120,399)	(147,075)
Special events, net	1,237,982	93,378	-	1,331,360	1,435,897
Contributions	660,830	2,522,483		3,183,313	1,763,224
Contracts	629,254			629,254	380,405
Interest and dividends	99,808	18,040		117,848	327,840
Conferences	-			-	98,408
Memorials and honoraria	64,898	4,486		69,384	97,218
Federated funding	39,193			39,193	49,688
Other income	2,351			2,351	1,404
Loss on disposal of fixed assets	(1,900)			(1,900)	
Net assets released from restrictions	1,526,124	(1,526,124)		-	-
Total revenue and support	4,258,540	1,112,263	-	5,370,803	4,154,084
Expenses					
Program services					
Research	2,469,977			2,469,977	1,706,805
Family services	805,022			805,022	608,533
Public health education	293,296			293,296	364,102
Government relations	146,913			146,913	126,441
Professional education	64,997			64,997	40,042
Total Program Services	3,780,205	-	-	3,780,205	2,845,923
Supporting Services					
Fundraising	640,458			640,458	593,713
Management and general	528,105			528,105	506,928
Total supporting services	1,168,563	-	-	1,168,563	1,100,641
Total expense	4,948,768	-	-	4,948,768	3,946,564
Change in net assets from operations	(690,228)	1,112,263	-	422,035	207,520
Net gain (loss) on investments	349,571	73,987		423,558	(407,455)
Change in net assets	(340,657)	1,186,250	-	845,593	(199,935)
Net assets, beginning of year	5,643,768	1,897,399	879,444	8,420,611	8,620,546
Net assets, end of year	\$ 5,303,111	\$ 3,083,649	\$ 879,444	\$ 9,266,204	\$8,420,611



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